

Inflammatory Bowel Disease (IBD) Patient Initiated Follow-Up (PIFU)

Other formats

If you need this information in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, please contact the PALS desk on 01392 402093 or at rduh.pals-eastern@nhs.net (for Mid Devon, East Devon and Exeter services) or on 01271 314090 or at rduh.pals-northern@nhs.net (for North Devon services).

What is Patient-Initiated Follow-Up (PIFU)?

Patient-initiated follow-up (PIFU) puts you, the patient, in control of when you are seen by the gastroenterology department. It means spending less time attending hospital appointments, but still having access to clinical support when you need it.

If your condition is stable, you may not find it helpful to attend regular outpatient appointments scheduled by the hospital. Sometimes, these appointments may not result in any change to your treatment, but you'll have spent time and energy putting arrangements in place to attend your appointment. Your condition may flare up in between regular booked appointments and it's at this point that you really do need our input. With PIFU, you can get advice from your clinical team, who may suggest an appointment is required.

You initiate the follow-up appointment, instead of the hospital, which is why this process is called patient-initiated follow-up (PIFU).

For all other concerns, or if you are feeling unwell, your GP will remain your first point of contact.

How will I know if I'm suitable for PIFU?

The IBD team will tell you if your condition is now suitable for PIFU, instead of regular appointments scheduled by the hospital.

It is entirely your decision. You can continue with regular appointments if you want to. Your clinician will have advised you about the PIFU process and given you this patient leaflet to support you.

When should I call for a PIFU?

You should call if you experience a flare-up of your symptoms.

We will provide you with rapid access to our specialist service if you are:

- unwell with symptoms of active IBD,
- have complications from your medications, or
- any other urgent IBD related concerns.

We can arrange investigation of your symptoms, review your medications and, if necessary, arrange urgent hospital review.

If you require urgent IBD advice outside of the IBD advice line opening times, you should contact your GP, NHS 111, your local walk-in centre or, if you are really unwell, your local Emergency Department (A&E).

How will I book a patient-initiated appointment?

This is a quick and easy process.

If you have a flare of your symptoms and need advice or an appointment, just follow the steps below and the team will help you.

5 easy steps:

1. Call the IBD advice line (Monday – Thursday 9am – 5pm, and Friday 9am – 2pm)
 - Royal Devon & Exeter Hospital: **01392 402728**
 - North Devon District Hospital: **01271 314005**

(Flare line is option 4)

This is an answer phone service; calls will be acknowledged and acted upon within three working days.

Please leave the following information:

- Your full name and date of birth
 - Your hospital number and/or NHS number
 - A telephone number so we can call you back during our opening hours
2. Explain to the IBD team you are having a flare-up and need some clinical advice.
 3. The team will review your concerns and decide whether you need immediate clinical advice for your symptoms or if you need an appointment. They may also organise investigations or tests
 4. If the team think you need an appointment, we will contact you to agree an appointment date and time. We will arrange an appointment for you within 10 working days.
 5. Attend your clinic appointment.

Will you still be looking after me if I'm on PIFU and don't initiate an appointment?

Yes, you will still have follow-up appointments with us. We will arrange a follow-up appointment after two years to check that your condition is still stable. If you are regularly seen in the advanced therapies clinic, we will arrange a yearly review.

If you have any concerns associated with your condition, but not a flare up, you can contact the IBD nurse specialists via the **My Care** patient portal.

If you have not yet signed up to the patient portal, further details can be found at www.royaldevon.nhs.uk/patients-visitors/my-care.

If you do not have internet access, please call IBD advice line (see page 2).

What if I am worried and change my mind about this style of follow-up?

Just tell us and we will go back to booking regular hospital appointments for you. Our team are happy to discuss any concerns with you.

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern, please contact:

PALS Mid Devon, East Devon and Exeter

- call 01392 402093 or email rduh.pals-eastern@nhs.net. You can also visit the PALS and Information Centre in person at the Royal Devon and Exeter Hospital in Wonford, Exeter.

PALS North Devon

- call 01271 314090 or email rduh.pals-northern@nhs.net. You can also visit the PALS and Information Centre in person at the North Devon District Hospital in Barnstaple.

Have your say

Royal Devon University Healthcare NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

Tell us about your experience of our services. Share your feedback on the Care Opinion website www.careopinion.org.uk.

Royal Devon University Healthcare NHS Foundation Trust

www.royaldevon.nhs.uk

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